

***THE MULTIPLE “A” SYSTEM  
OF SERVICE DELIVERY FOR ADOLESCENTS AND  
ADULTS WITH FASD:***

***© Jan Lutke***

<b><i>ACCESSABILITY</i></b>	<b><i>AS NEEDED</i></b>	<b><i>ADVOCACY</i></b>
<b><i>AFFORDABILITY</i></b>	<b><i>AMOUNT</i></b>	<b><i>AUTHORITY</i></b>
<b><i>AVAILABILITY</i></b>	<b><i>ADAPTABILITY</i></b>	<b><i>ACCOUNTABILITY</i></b>
<b><i>ACCEPTABILITY</i></b>	<b><i>ACTION ORIENTED</i></b>	
<b><i>ADDRESS NEED</i></b>	<b><i>ANCHORPOINT</i></b>	

In the thirty years since FASD was ‘discovered’, an entire generation of individuals has reached adulthood. Some are in their thirties. A second generation is now in their twenties and a third generation is very close behind. This suggests all of them were infants when diagnosed – a fact we know to be in error.

Many children were, and are, diagnosed at much older ages, and thus require specialized adult services before the generation gap closes. Others who came very late to diagnosis are already into their forties, and yes, even their fifties. This tidal wave of alcohol affected adults now hitting shore *must* be addressed if they – and we - are not to be swept out to sea.

It is now well understood that individuals with FASD have a permanent *birth defect* disability. The primary and most important locus of the birth defect is in the brain. For the majority it *does not* include a diagnosis of mental handicap by standard definitions. In the larger world, it simply does not matter if the person has a slightly different face (which largely disappears with age) or may be somewhat shorter than others. Additional alcohol related birth defects (ARBD’s) such as heart or bone defects can be, and by adulthood likely will have been, surgically corrected or medically treated. Ultimately, the only thing that really matters is how the brain works, how the brain does not work, or how the brain works differently from the norm. Ultimately, society and its systems must accept that is the *way it is now, and the way it will always be*.

The brain damage will not be “quick fixed”. No magic bullet will repair the damage. It is simply not possible to “correct” the way in which the brain developed prenatally, that:

- the brain as a whole is too small
- individual portions of the brain themselves are too small or the wrong shape;

- neurons do not talk to each other,
- brain chemistry is different,
- cells are not where they are supposed to be.

The very best science can do is to attempt to manage some of the neurochemical differences which may present as anxiety, depression and apparent ADHD difficulties. Management may be fairly limited, and frequently with only temporary success. There is no known medical intervention that can modify the individual's ability to think better, understand, cope, adapt, or remember, There are all skills that are absolutely essential for *successful* independent, autonomous function that is generally socially sanctioned and rewarded in our society.

Currently, only those adolescents and adults who have intellectual quotient (IQ) scores below 70 qualify for support services within the social service field. These services are available to others who are mentally handicapped, however limited these services might be. Most of the adolescents with FASD do not qualify for true special education services in school if, indeed, they are actually still in school. Most are simplistically seen as *behaviour* problems for which consequences and penalties are imposed in increasingly harsher amounts. Adult education, pre-vocational or vocational programming for those with FASD is virtually non-existent.

Legal diversion for those in trouble with the law rarely happens. The legal system has few, if any, alternative sentencing options. In jails, there is no FASD specific programming. Cognitively based behavioural approaches commonly used in Canadian prisons are not effective with FASD.

Supported employment is a myth. Adults with FASD are only *a parent away from being homeless*. And parents, who and if they are still involved, are almost always so stretched financially, emotionally, socially and psychologically attempting to provide for the on-going needs of their adult son or daughter that they, themselves, are close to the line. In the absence of supports, it becomes almost impossible to continue. They have no reserve left to care for their children. Is it any wonder that these lay traditional 'support systems' so frequently collapse?

We cannot even begin to address the critical issues of mental health, addictions, parenting or involvement in the legal system until we provide for these absolute bare minimums of basic of daily living:

- education
- finances
- employment
- housing
- health
- family support

Currently, there is only a small handful of any type of FASD specific programs providing any kind of service to adolescents or adults with FASD, anywhere. Those few that do exist are all limited to short term project funding.

What is needed is a thoughtful, planned, systematic, *all-systems-wide, 20 year design with comprehensive, permanently committed funding designated to FASD-specific designed, developed and implemented programs everywhere they are needed. One size clearly does not fit all. Planning must take this into account.*

As expensive as this will be, it is likely to be *far* less expensive than the cost of doing what clearly is not working.

## **A**CCESSIBILITY

Accessibility equals eligibility. One simply cannot access support or a program if one is deemed not to be eligible for it. Arbitrary existing policies in all systems must undergo a thorough review. System-wide changes must be made to accommodate those with FASD, with eligibility determined by adaptive functioning rather than an arbitrary IQ model.

## **A**FFORDABILITY

Families of adolescents and adults, and adults without families must be able to afford services. For adults on their own, there is simply no question that none of them have the financial resources to purchase needed supports.

Families, except in exceptional situations, have very limited or no access to disposable income that can be used to purchase diagnostic, assessment or support services for either the affected adolescent or adult or the family unit itself. Family breakdown is directly related to the absence of supports. The difficulty in maintaining and the repeated loss of residential placement for adolescents and adults is directly related to the absence of consistent supports. Although all service delivery is expensive, it is cost-prohibitive to society to ignore the cost efficiencies that could be accrued through the provision of proactive and effective support services. Society can pay now, or it can pay *now*. There is really no such thing as “pay later”.

## **A**VAILABILITY

Services in all systems must be available in actuality, not simply on paper. That means they must be designated, and funded, as the *specific* responsibility of *specific* departments, agencies, organizations and individuals. The responsibility for FASD needs to be acknowledged as a job within itself, *not* run off the side of someone else's desk. The authority to act must rest within these jurisdictions.

## **A**CCCEPTABILITY

All services must take into account the personal, social, geographical and cultural circumstances of the individual and family. People with FASD and their families are not necessarily a homogeneous group, so great sensitivity is required.

## **A**DDRESS NEED

Supports and services must address what is actually needed by both families and affected adolescents and adults. Individuals and families with FASD are not all the same. The service required by one family or individual is not what is needed by or will necessarily work for another. A significant range of different options must be available in order that a family or individual can choose what is acceptable and most useful to them.

## **A**S NEEDED

Services and supports need to be there when they are needed, as soon as they are needed. Proper planning would establish services *before* they are urgently needed. Wait-listing individuals and families who are in crisis is simply not an option. Quick access to services is key to preventing deterioration in both the individual and the family. It leads to significant additional costs to systems.

## **A**MOUNT

Simply put: there is a large population of people with FASD. We require equivalent diagnostic and support services. Short changing supply will *not* reduce demand. It will simply overload more costly systems where it will have to be accommodated by default (ie: legal system).

## **A**DAPTABILITY

What works today is not what will work next month or next year. Service delivery must be fluid, flexible and not bound by rigid parameters limiting what can or cannot be done. Easy transition between systems, services and service providers must be provided. Inter-agency and inter-system cooperation, collaboration and communication is essential. Territoriality must be avoided. Funding directives need to reflect this.

## **A**CTION ORIENTED

Systems must learn to act now, and act fast. Waiting for “evidence based practice” to lead the way is a costly mistake we can no longer afford. There is plenty of “practice-based evidence” as to what needs to be done to get on with the task.

## **A**NCORPOINT

Systems, organizations, agencies and individual professionals must come together to provide an anchor point for both affected individuals and families. An anchor point is the place within the circle of supports that can best be expected to remain constant and stable over time, where change is minimal and knowledge, skills, abilities and experience in the area of FASD are the highest. *It is usually the place where individuals and families feel most comfortable and where they feel the safest.*

## **A**DVOCACY

All systems would do well to incorporate the role of an ‘FASD Advocate’ within their mandates. One clearly designated and FASD- knowledgeable person to whom all others, both within the system and without, could turn to for advice, clarification, referral, mediation, appeal and arbitration would likely work to the advantage of everyone.

## **A**UTHORITY

The time for buck passing is past. Those with the authority to make change *must use it and do so*. Governments must use their authority to fund service delivery. Systems and system managers must delegate power and authority from the top to those front-line workers who need to be able to make financial decisions in order to provide supports and services as they are needed.

## **A**CCOUNTABILITY

Systems must learn that they are, in fact, accountable to those they serve. They must actually, and in usable fashion, provide what they say they do. They need to stop believing the myth that if it is down on paper, it actually exists and actually works, when it does not.

Families who receive services must learn that they, too, are accountable for what they use and how they use it.

And all of us, both service providers and family members, must learn that we are accountable to the adolescents and adults with FASD for: what we say, what we do, and how we do it

People with FASD have permanent, irreversible brain damage. They do not outgrow it. You cannot 'fix' it. You cannot love it away, punish it away, or ignore it away. You can, however, provide the types of long-term intervention, supports, structure, supervision and services that encourage, promote, support and *allow* for adequate function.

This is the point at which adults with FASD will take their rightful place as contributing, productive, accepted and valued *mainstream* members of society, with dignity, self-respect and self-esteem.